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AUTHOR Capie, Angus
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ABSTRACT

This booklet first looks at principles in evaluating services for people with mental retardation and strategies for evaluating and monitoring community services. It then describes two programs which involve parents/families in the evaluation and monitoring of community services in New Zealand. Basic principles include the importance of written standards, development of policy by service users, and linking of evaluation/monitoring systems with government standards. Several existing evaluation systems and accreditation procedures are briefly summarized. A two-level evaluation and monitoring system for community homes has been developed in New Zealand. At Level 1 local parents/consumers monitor homes and day programs on a frequent basis using a Key Points protocol which focuses on three areas: (1) the environment, (2) options and activities, and (3) management and staff. Training is provided for the parents, consumers, and volunteers who constitute these teams. At Level 2 less frequent but more comprehensive evaluations, also with heavy parent and consumer participation, assess quality of life issues by means of a 10-step process. The final section of the booklet lists lessons learned from implementation over the past 12 years including the low cost, less than 1 percent of total program costs on a nationwide level. An appendix lists other evaluation and monitoring methods. (Contains 14 references.) (DB)

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Evaluating and Monitoring Community Services for People with Mental Handicap

A partnership approach: the New Zealand experience

by Angus Capie

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International League of Societies for Persons with Mental Handicap

Evaluating And Monitoring Community Services For People With A Mental Handicap

A Partnership Approach
The New Zealand Experience

A document
prepared by
Angus Capie, Director
Standards and Monitoring Services
(New Zealand)

1992

International League of Societies
for Persons with Mental Handicap
248 Avenue Louise, Box 17
B-1050 Brussels (Belgium)

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Terminology

"Evaluation" and "Monitoring" are words that are often used interchangeably. Although we generally use the term "Evaluation and Monitoring" in all our work, strictly speaking we would use "evaluation" to describe a full length examination of a service designed not only to see that adequate standards exist but designed also to help new developments take place within a service.

We use the term "monitoring" to describe the short examination of services made by teams on a regular basis. Such teams essentially focus on monitoring that adequate standards exist. If they feel the service needs a major revamp they will request a full scale evaluation.

Foreword by the President of the ILSMH

In 1988 the League first published "Quality Evaluation Guidelines". I am pleased that we are now able to publish this practical description of the methods used in New Zealand to evaluate services using parents,consumers and staff working together.

In 1991 as President of the League I was able to visit New Zealand and was encouraged to find that, at the opposite end of the earth, NZ supports community living services, and has developed a sophisticated system for evaluating and monitoring services.

I believe we can all learn how to improve services by studying this booklet and thank my friend Angus Capie for sharing "the New Zealand Experience".

Victor Wahlström
Stockholm 1992

1. Developing an evaluation and monitoring programme for community services

The second half of the Twentieth Century has seen a continuous and almost universal commitment to the provision of services for people with mental handicaps in community settings.

Countries that for a hundred years had kept people in segregated institutions, hospitals or training centres, have almost all sought ways of integrating people with mental handicaps back into ordinary living situations.

Countries that for various reasons have never possessed traditional mental handicap hospitals have begun to develop community services.

This move into community living stemmed from a number of developments internationally, but primarily from

a) the demands made by the international parents' movements that developed around 1950 (Beasley 1979)

b) the acceptance of Normalization theory spelt out by Bank-Mikkelsen (1969) and Bengt Nirje (1969) in Scandanavia in the 1960's, and by Wolfensberger (1972) in North America a few years later.

In North America the parallel emergence of the Civil Rights Movement undoubtedly assisted the cause of people with mental handicaps.

Although most parents and families are very supportive of community living, it is widely recognized that simply living in a house in an ordinary street does not necessarily mean one becomes

part of the community. Many families and advocates are concerned that small community homes may become isolated and that there is an increased danger of poor standards developing in such situations.

For over twenty years it has been recognized that as we develop small community services we should also develop ways of monitoring the services to ensure that the basic standards we seek are maintained. It is also recognized that services should be evaluated regularly to see how service providers can develop more responsive services. The challenge today is not simply to work out ways of monitoring and evaluating services - that is no great problem. The real challenge lies in being able to do three things:

1) Develop strategies that enable services to be monitored regularly.

2) Enable consumers and their families to determine what is appropriate in these services.

3) Allow developmental evaluations to assist service providers to maintain quality at an affordable cost.

In this document we will look at some of the principles involved in evaluating services, and examine some strategies developed to evaluate and monitor a range of community services. We shall also describe in some detail two programmes developed with parents/families that are being used to evaluate and monitor community services throughout New Zealand.

2. Principles involved in developing evaluation strategies

Many different methods have been developed for evaluating and monitoring community services (a few examples are listed in Appendix I).

Some programmes have been exceedingly expensive and complex. Others have consisted simply of short checklists given to parents/volunteers without at the same time, giving them any training or guidance in how the Checklists could best be used.

Parents, family members and volunteers, like staff with professional training, should not be expected to participate in service evaluation without having undertaken an appropriate training programme. Such training is necessary to ensure consistency in approach, clarity in results, and to ensure that everyone understands that the task is one that is itself valued.

BASIC PRINCIPLES

1. The Society or Agency must have some written standards, or a philosophy and policy which tells members, service users, staff, and the funding agencies what is acceptable. It is not possible to evaluate a service without standards based on a clear philosophy.

Examples of such statements are the Canadian Association for Community Living's "Community Living 2000" (1987), and IHC's New Zealand Philosophy and Policy (1990).

Standards statements will vary from culture to culture, and will also be influenced by the economic state of a country. It is clearly inappropriate to have a standard for a community service that

demands material standards that are significantly better than those enjoyed by ordinary residents of that community.

2. The philosophy/policy should be determined and developed by users of the service, their families and advocates.

Most countries which developed segregated services did not do so at the request of families, but rather because of the advice of professionals, believing that "professionals know best" (See Wolfensberger, 1975). As a result people were removed from their family networks - often at a large emotional cost to the family, and at a large financial cost to the country. The failure of professionals to accept the desires of families/advocates for nonsegregated services is regrettable but common. Professionals must recognize the on-going interest and role of family members in service quality.

3. Although the evaluation and monitoring system must reflect the preferences of service users (consumers), wherever possible it should be linked in with government standards. Where a government has not yet clearly spelt out 'Standards for Community Services', agencies should invest time in seeking government support for such Standards. Government support for community living programmes can help everyone.

SOME SYSTEMS OF EVALUATION

The development world wide of a range of community services owes a great deal to the many unheralded and unpublicized parents who dared to challenge "the Establishment" and "the Medical Model" by campaigning for community options. The progress made in

community living also owes a great deal to Wolf Wolfensberger and his associates (1973, 1975).

Wolfensberger further developed Normalization theory, and later, argued that it was more useful to refer to Normalization as Social Role Valorisation (Wolfensberger, 1983).

PASS and PASSING

Wolfensberger and colleagues developed two methods for evaluating the quality of human services - PASS (Program Analysis of Service Systems) and PASSING (Program Analysis of Service Systems: Implementation of Normalization Goals). Both systems follow essentially the same procedure, although they use different measurements of service quality.

PASSING (Wolfensberger and Thomas 1983) is an approach that all service providers and evaluators should examine carefully. PASSING states it has two major purposes:

1. To assess the normalization quality of any human service,

2. To teach the principle of normalization." Wolfensberger and Thomas describe in detail the whole rationale for PASSING. It is interesting to note that PASSING does not attach any special virtue in using parents or family members. It emphasizes that Team Members must have undergone an approved PASSING training event.

In an effort to ensure that the principles are not watered down, materials used and strategies applied in PASSING are rigidly controlled.

In New Zealand we found this limited our use of the material in evaluation and monitoring services.

OTHER APPROACHES - ACCREDITATION PROCEDURES

In a range of countries, governments have supported the establishment of Councils which are empowered to decide whether a service provider should continue to receive government funds.

An example of this approach is seen in the "Standards for Services for People with Developmental Disabilities" (ACDD 1990). Such procedures are designed to ensure government funding is directed to services that meet stipulated conditions.

This may ensure that at the time of accreditation the quality of service is high, but does not necessarily guarantee monitoring of service quality between accreditation visits. Family members or workers in the field will tell everyone of how quickly quality can change. Furthermore, the complexity of the Accreditation model, and the high costs involved, mean that in many places Accreditation is not a viable proposition.

CONSUMER INVOLVEMENT

Some accreditation procedures also insist that the team members or "surveyors" must be people with professional training in a discipline traditionally associated with this field. It could be argued that such

a policy devalues the role that family members can have in ensuring the needs of families are well met. Parents of people with a mental handicap often feel shut out by such procedures. Professionals come, professionals go, but families are there for ever, and although they acknowledge there is much they can learn from professionals, we believe that parents' knowledge base about their son/daughter/sibling is of significant value and ultimately should be acknowledged in service planning.

A further development of the policy of consumer involvement has been an increasing commitment to involving people with mental handicaps themselves in both developing policy and in being members of evaluation and monitoring teams. A separate monograph describing work in this area is in preparation.

3. A consumer controlled approach - the New Zealand experience

New Zealand - a small South Pacific nation (population = 3 million) - established its major Parent organization (now known as IHC) for people with a mental handicap in 1949 .

As successive governments failed to provide alternatives to institutions, IHC began to establish a range of educational, residential and day programmes.

When the government accepted that the provision of education was a state obligation for all in 1989, IHC transferred all its educational services to the State Education sector.

Today IHC provides residential services for 3000 people and day programmes for over 4000 adults. Day programmes vary from sheltered workshops to supported employment programmes.

Residential services range from supporting people living without live-in staff in apartments, to homes that have staff 24 hours a day 7 days a week. Virtually all homes have 5 or fewer residents.

In the late 1970's, influenced by the work of the Canadian National Institute for Mental Retardation (now the G. Allan Roeher Institute), a NZ group began to develop evaluation procedures for community homes (Standards for Residential Services, 1979).

Many of the procedures and practices were a direct reflection of the work done in Canada. From the beginning of the NZ effort, however, parents/family members were seen as essential partners in the operation.

This programme for evaluation of residential services in IHC, although it went a long way in helping IHC develop its residential philosophies, had a number of deficiencies. By evaluating residential homes singly, it proved expensive and unable to regularly review all programmes. By focussing on residential services, it tended to ignore what happened to people away from their homes.

A review of progress being made led to the development of a two tier evaluation and monitoring system.

a) Level One (KEYPOINTS) enables more frequent monitoring programmes to be carried out
b) Level Two (PREM) consists of less frequent but more comprehensive evaluations that assess the quality of life that people are receiving across services.

KEY POINTS PROCEDURES

It was agreed that parents, advocates, and consumers trained in monitoring services should take responsibility for ensuring that all local services were reviewed regularly, and thus see that these services met all basic standards.

At a local level, all homes and day programmes would be reviewed by local parents/consumers using KEY POINTS procedures. No one could participate without training, and parents/staff accepted that people with mental handicaps would be key participants.

This was seen as being a particularly appropriate area in which people with mental handicaps could begin to participate directly in monitoring services.

KEY POINTS MONITORING

Monitoring local services to ensure that they are maintaining a satisfactory standard involves teams of usually 3 people (ideally a parent, a volunteer and a person with a mental handicap) in a short 2-3 hour visit to the service. The team systematically focuses on 3 major areas:

a. The Environment - what does the service look and feel like? Does it reflect the cultural values of the residents?

b. Options and Activities - Do people have a say in the things in life that are important to them?

c. Management and Staff - Do the people who work in the service get the support and training they need?

After the team's visit (and ideally every service should be visited at least every 6 months) a brief report commenting on services is produced.

This may commend staff for some innovative actions, and will often suggest minor changes in the service. If the team is not satisfied with the service, it can ask that a full evaluation be undertaken.

TRAINING TEAM MEMBERS

Parents, consumers and volunteers who wish to take part in Key Points monitoring have to undergo training. A typical Introductory Training Seminar would be as follows:

5.45 PM Introductions

6.00 PM An Introductory Session on Key Points Monitoring
- values - an introduction
- its purpose
- confidentiality
- observing
- asking questions/listening

7.15 PM A light meal provided

8.00 PM Visit the service in teams, with an experienced team leader, to practice using the Checklist and methods

9.00 PM Reporting
- Discuss findings with other team members
- Agree on what should be in a report
- Write a mock report

9.30 PM Conclusion
- Share ideas
- Protocol and Procedures
- Evaluation of session

Initial Training Sessions may run from 10am to 5pm or over some evenings depending on what consumers want.

On successful completion of such a session, participants may then move into observer status on teams, and receive further training sessions, before becoming team members. Not all people who volunteer for training become service evaluators. Those who are selected after preliminary training receive on-going support.

Keypoints has proved to be a cost effective way of monitoring services on a regular basis.

THE PREM PROGRAMME

IHC always recognized that although regular monitoring of quality was necessary, it was also desirable that a procedure for more in-depth evaluation of services should be developed.

IHC's National Director (Munro 1987) asked that steps be taken to ensure:

a) the evaluations were removed from the services division of IHC.

b) they provide his staff with ways of developing and improving services.

It was therefore decided to establish a new parent body, called the Standards and Monitoring Board, that was independent of all service providers, and give it responsibility for developing a system for evaluating services in depth.

This was done through a staff/volunteer structure, known as Standards and Monitoring Services (SAMS). SAMS has a Director and a number of regional staff, as well as a number of regional

Evaluation and Monitoring Coordinators (usually parents of people with mental handicaps), who are trained and experienced in conducting evaluations.

This programme now known as PREM (Procedure for Evaluation and Monitoring), uses teams of trained people led by a Coordinator, to evaluate a range of community services used by people with a mental handicap. After a 3 or 4 day study visit, teams report back with recommendations.

A PREM EVALUATION

The PREM programme is flexible and it fits in with varying demands from the community. Although firmly committed to seeing that the emphasis remains on a parent/staff partnership, we know that it enables a wide range of people to participate and that it can easily be adapted to encompass different cultural values in other societies.

When PREM was first developed it tended to focus strongly on what was happening to all people in a particular service, be it home or day programme. Experience has shown us that it is more useful if we randomly select some service users, and then evaluate the total lifestyle they are able to enjoy, irrespective of their main base.

The following outline illustrates a typical PREM evaluation.

STEPS IN A PREM EVALUATION.

1. Co-ordinator is advised of agency/service to be evaluated.

2. Co-ordinator collects standard set of information about the service, including names of service users, family members and staff in the service.

3. Co-ordinator selects team members from trained pool available. Selection is influenced by the nature of services being evaluated and experiences of team members.

4. Interview schedule for evaluation is arranged, and team members briefed.

5. Team members visit referred service, and other services or establishments that are providing services for the selected group of consumers whose life styles are being evaluated. Such services may include Day Programme Centres, Tertiary Education Centres, Employers.

6. Team interviews consumers, parents, family members and friends, plus staff of the agency.

7. Team meets after visit and agrees on content of Draft report.

8. Draft report sent to service provider.

9. Meeting held with service provider and users to finalize report.

10. Report finalized and schedule agreed for implementing the recommendations of the report.

SERVICE DEVELOPMENT

The focus of PREM is on how we can best help service providers do better.

Service providers therefore negotiate with the teams as to how services might be best developed. PREM teams do not have power to cut off funding - indeed they do not seek this power. However if any service fails to meet minimum standards then a team may recommend that the Government funding agency should consider such action.

PREM teams emphasize that evaluation is about improving the quality of services. Parent/consumer controlled evaluation and monitoring aims to see that the quality of life offered to people with a mental handicap is maintained and improved. We believe this can only be achieved by co-operation with service providers.

4. The way ahead

Collection of data about quality of services over a period of twelve years has taught us a number of things:

1. Evaluation and Monitoring of services need not be expensive. In NZ it costs less than 1% of the total cost of providing services to run a nation-wide evaluation programme.

2. Evaluation and Monitoring is best developed and controlled by parents, consumers, families and staff working in partnership. Where evaluation is controlled only by professionals, it becomes so expensive that most places cannot afford it on a regular basis. A programme like PREM is a positive and valued means by which families can influence service provision.

3. Evaluation and Monitoring will be more successful if it is done in partnership with government, eg. in New Zealand we have worked in partnership with the government to develop a Standards Document for Residential Services that reflects closely the basic philosophies on which PREM is based.

4. Evaluation and Monitoring team members must be trained. Although we recognize the ongoing involvement of parents in the lives of their family member, we also recognize that everyone must be trained for the specific application of their own knowledge to an Evaluation and Monitoring situation.

5. Although initially parent controlled organisations may be the ones most willing to look at Evaluation and Monitoring in this way, (as distinct from a process for meeting government standards), it is possible with a combination of persuasion and

encourage other providers - private or public - to believe that regular evaluation of services is not only good for the clients, but good for the providers. To this end it is important to foster a working partnership with service providers.

6. It is necessary to ensure that resources are available for the the on-going support of parents and others. Practices and policies evolve, and everyone needs continuing opportunities to learn.

7. Procedures such as PREM and KEYPOINTS are effective but can only remain so if all concerned make a real commitment. Boards of evaluation agencies must value and support parent/family involvement.

8. Service providers are constantly being challenged by users to enhance and develop services. It is equally important that those involved in evaluation and monitoring are also prepared to continually update methods and systems.

References

Bank-Mikkelsen, N.E., Denmark, in R.B. Kugel & A. Shearer (eds), Changing Patterns in Residential Services for the Mentally Retarded. Presidents Committee on Mental Retardation, Washington D.C. 1969.

Beasley, D.M.G. The Integration of the Mentally Retarded in our Community. Paper presented at 4th Asian Conference on Mental Retardation, K.L., 1979.

Cerreto, Mary C., Value Based Service Delivery, The Accreditation Council on Services for People with Developmental Disabilities, 1988.

Community Living 2000, Canadian Association for Community Living, Downsview, Ontario, 1987.

Munro, J.B., IHC, Wellington, New Zealand, 1987. Personal communication.

Nirje, Bengt, The Normalization Principle and Its Human Management Implications in R. Kugel, and W. Wolfensberger (eds), Changing Patterns in Residential Services for the Mentally Retarded. President's Committee on Mental Retardation, Washington D.C. 1969.

Nirje, Bengt, The Basis and Logic of the Normalization Principle, Australian and New Zealand Journal of Developmental Disabilities, Vol 11/2, 1983.

Philosophy and Policy, New Zealand Society for the Intellectually Handicapped (Inc), Wellington, New Zealand, 1990.

Standards for Residential Services, NZIMR, New Zealand, 1980.

Wolfensberger, Wolf, The Principle of Normalization in Human Services. National Institute of Mental Retardation, Downsview, Toronto, 1972.

Wolfensberger, Wolf, The Origin and Nature of our Institutional Models. Human Policy Press, New York, 1975.

Wolfensberger, Wolf, Social Role Valorisation: a Proposed New Term for the Principle of Normalization, Mental Retardation, 21(6), 235-239, 1983.

Wolfensberger, Wolf and Glenn, Linda, PASS: a method for the quantitative evaluation of human services, National Institute of Mental Retardation, Downsview, Toronto, 1973.

Wolfensberger, Wolf, and Thomas, Susan, PASSING, a method for the quantitative evaluation of human services, National Institute of Mental Retardation, Downsview, Toronto, 1983.

Appendix I - some examples of evaluation and monitoring methods

Accreditation Council on Services for People with Developmental Disabilities, Standards for Services for People with Developmental Disabilities, Boston, 1987, 1990.

Allen, W. and Gardner, N. An ANDI workbook for looking at places where people live and work, Napa, California, 1983.

Bersani, Hank A. Assuring Residential Quality: Issues, Approaches and Instruments, Center on Human Policy, New York, 1989.

Bersani, Hank A. Monitoring Community Residences: Handbook and Guidelines, ARC-Ohio, Columbus, Ohio, 1984.

Capie, A.C.M., Hartnett, F. and Craig, M. PREM III Checklist and Procedure, Standards and Monitoring Board (in press), Wellington, New Zealand, 1990.

Flynn, A. and Weiss, S. A Normalisation and development instrument (2nd ed.) (ANDI), Sacramento, California, 1977.

A Guide to Service Quality Review, (Rev. Ed), State of Connecticut Department of Mental Retardation, Unpublished, Connecticut, 1991.

Pelletier, J. Quality Evaluation Guidelines, International League of Societies for Persons with Mental Handicaps, 1987.

Rocco, B. and Capie, A.C.M. KEY POINTS Checklist and Procedure, Standards and Monitoring Board (in press), Wellington, New Zealand, 1992.

Taylor, Stephen J. and Bogdan, Robert. Observing Community Residences, Center on Human Policy, New York, 1990.

Standards and Monitoring Services (SAMS) was established as a separate parent controlled body by IHC, New Zealand's major organisation for people with a mental handicap.

A major objective of SAMS is to work with service providers to improve the quality of services offered to people with a mental handicap.

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The International League of Societies for Persons with Mental Handicap (ILSMH)

Founded in 1960 by representatives of societies of parents of mentally handicapped persons, friends and professionals in the field of mental retardation, the ILSMH is devoted to defending the rights and interests of mentally handicapped persons without regard to nationality, race or religion. The League addresses problems related to mental retardation: among them are prevention, diagnosis and early treatment, education and training, economic security, social welfare and integration, guardianship, interfamilial relations, due process of law and public education.

The main objectives of the League are:

— to determine, with the help of persons with mental handicap, their families and specialists, what is required for these persons to live as close to normal lives as possible;
— to disseminate helpful information to and promote contact between member societies;
— to encourage the creation of new societies;
— to initiate and develop contacts with international organisations, governmental and non-governmental, in order to speak on behalf of member societies;
— to promulgate the basic principles set forth in the UN Declaration on the Rights of Mentally Retarded Persons.

To achieve these objectives, the League, with the help of its member societies, organizes international symposia of experts, regional conferences and world congresses. The League publishes the results of these efforts, an international newsletter translated in four languages, and various pamphlets on topics of general interest. The League has consultative status with UNESCO, UNICEF, ILO, WHO, ECOSOC and the Council of Europe, and has official relations with the European Communities and other international organizations interested in handicapped persons.

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B-1050 Brussels (Belgium)

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